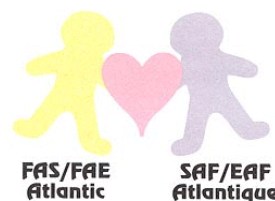


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## FAS/FAE INFORMATION TOOL KIT



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### CONTENTS:

#### Backgrounder:

- Purpose of the Fetal Alcohol Syndrome Tool Kit

#### Fact Sheets:

- What are FAS/FAE?
- FAS/FAE: What are the numbers?
- FAS/FAE high-risk groups
- Economic cost of FAS/FAE
- FAS/FAE prevention efforts
- Recommendations for action

#### Bibliography

#### Resources and Contacts:

- FAS/FAE Resources
- Order Form: Directory of FAS/FAE Information and Support Services in Canada

#### Presentation:

- FAS/FAE (PowerPoint presentation)

#### Diskette:

- Fact sheets (in WordPerfect) *factsheets.wpd*
- Resource list (in WordPerfect) *resource.wpd*
- Presentation (in PowerPoint) *fas.ppt*
- Presentation (in WordPerfect) *fas\_slides.wpd*
- Presentation (in Word) *fas\_slides.doc*

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Population and Public Health Branch  
First Nations and Inuit Health Branch  
Atlantic Region  
Health Canada

March 2003



## **BACKGROUND**

### **PURPOSE OF THE FETAL ALCOHOL SYNDROME TOOL KIT**

In February 2000, the Population and Public Health Branch and the First Nations and Inuit Health Branch of Health Canada in the Atlantic Region funded the FAS/FAE Atlantic Forum. Since the Forum, a number of events and activities have taken place in the Atlantic region which have helped promote work in the area of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), including the Provincial Symposium –Alcohol Related Birth Defects held in Gander, Newfoundland in March 2001. This symposium was funded by Health Canada along with other partners, including sponsors from both the provincial and private sectors.

In 2001, the Population and Public Health Branch, Atlantic Regional Office (PPHB Atlantic) was also able to fund the Federation of Foster Families of Nova Scotia to create a Participant's Manual for the Fetal Alcohol Syndrome/Fetal Alcohol Effects Training Program for Foster Parents. In working with the Fetal Alcohol Syndrome Intergovernmental Committee and through its work with various communities and agencies, PPHB Atlantic identified a gap hindering the further progression of work related to FAS/FAE in the Atlantic region.

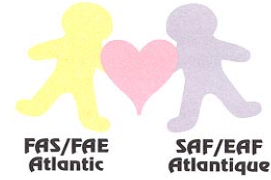
To address this need, PPHB Atlantic, along with the First Nations and Inuit Health Branch, Atlantic Region, agreed to develop an information tool kit to help the different stakeholders in the Atlantic region to build a case for their work related to FAS/FAE. These stakeholders include the provincial governments, non-governmental organizations and non-profit organizations.

It is hoped that this FAS/FAE Information Tool Kit will be used by stakeholders to promote their work related to FAS/FAE, and to create awareness of the effects of fetal alcohol exposure.



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## WHAT ARE FAS/FAE?



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***Fetal Alcohol Syndrome (FAS)*** and ***Fetal Alcohol Effects (FAE)*** are the birth defects caused by alcohol use during pregnancy. The effects of prenatal alcohol exposure on the developing fetus are dependent on the amount of alcohol consumed, and the pattern and frequency of drinking.

***FAS*** is a medical diagnosis that can only be made when there is a confirmed history of fetal alcohol exposure. The three essential traits that identify FAS are:

- prenatal and/or postnatal growth retardation
- central nervous system deficits
- characteristic facial features.

***FAE*** or ***partial Fetal Alcohol Syndrome (pFAS)*** are used to describe the presence of some, but not all, FAS characteristics. FAE and pFAS are not necessarily milder forms of FAS. The symptoms of FAE and pFAS may be severe. A diagnosis of FAE or pFAS also requires a confirmed history of prenatal alcohol exposure.

Prenatal alcohol exposure is the leading cause of birth defects in the developed world.

Prenatal exposure to alcohol can cause:

- intellectual deficits and learning disabilities
- physical disabilities including heart defects, cleft lip and palate, spina bifida, cysts or cavities in the brain, vision problems, kidney problems, liver defects, hernias, seizure disorders, skeletal problems and other physical abnormalities
- hyperactivity
- attention and/or memory deficits
- inability to manage anger
- difficulties with problem solving
- prenatal and postnatal growth deficiencies.

Potential secondary conditions can include:

- early school drop out
- alcohol and drug abuse
- problems securing and maintaining employment
- homelessness
- trouble with the law
- mental health problems.

The internationally recognized rate of occurrence of FAS is 1 to 3 per 1,000 live births. The incidence of FAE is believed to be at least three times higher than FAS; all disabilities resulting from prenatal alcohol exposure are estimated at 9.1 per 1,000.<sup>1</sup>

FAS, and all damage caused by prenatal alcohol exposure, are preventable.

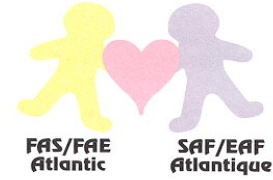
FAS cannot be cured, but the effects of the disabilities can be managed.

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<sup>1</sup> P. D. Sampson, A. Streissguth, F. Bookstein, R. Little, S. Clarren, P. Dehaene, J. Hanson and J. Graham Jr., "Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder," *Teratology*, Vol. 56, No. 5, November 1997.

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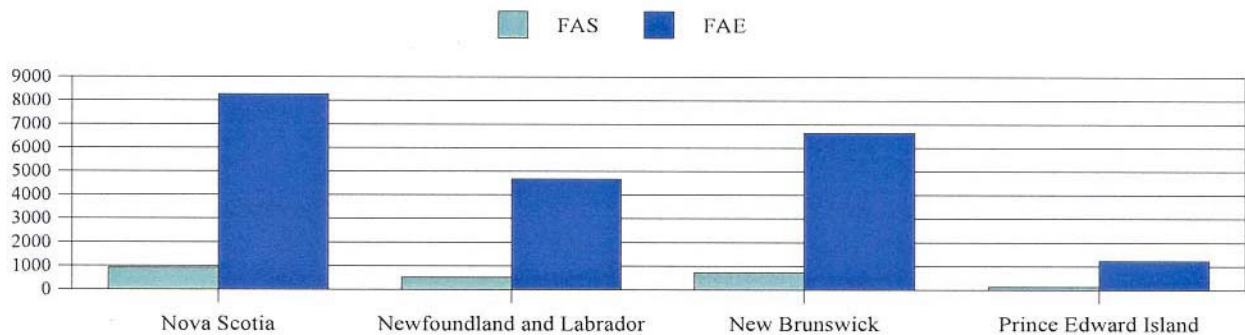
## FAS/FAE: WHAT ARE THE NUMBERS?



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There are many different estimates of the incidence rates of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). The internationally accepted incidence rate of FAS is between 1 and 3 per 1,000 live births. The rate of alcohol-related neurodevelopmental disorders is estimated at 9.1 per 1,000.<sup>1</sup> This rate is widely used to estimate the rate of FAE.

Applying the conservative rate of 1 per 1,000 to Atlantic Canada's population, approximately 2,300 people in the four Atlantic provinces have FAS, and as many as 20,800 have FAE, using the rate of 9.1 per 1,000.



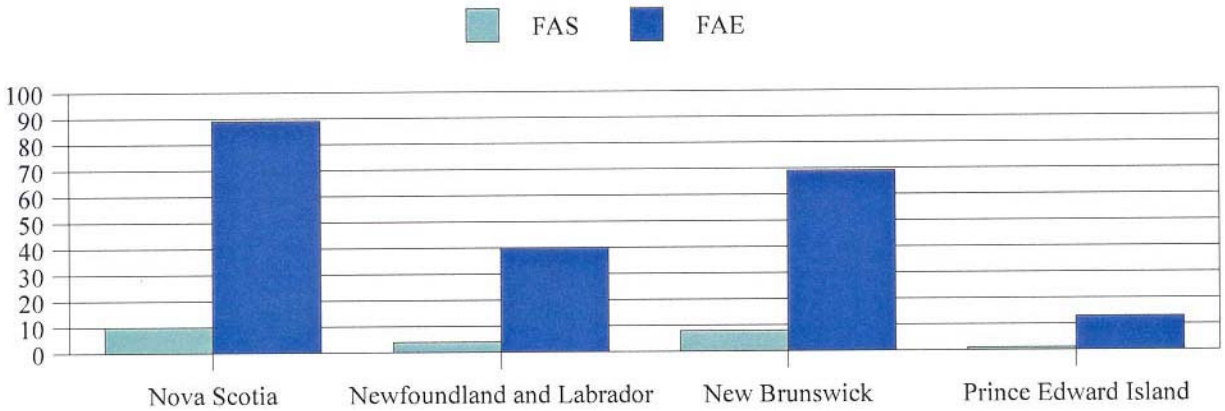
Source: 2001 Census of Canada (population data)

**Figure 1: Estimated Number of People Affected by FAS and FAE, Atlantic Provinces, 2001**

Figure 1 shows a very conservative estimate of the number who have FAS in each of the Atlantic provinces, and the number who are estimated to have FAE. (This estimate uses the rate of FAS of 1 per 1,000, making it a conservative estimate of the number of people with FAS. The population data is from the 2001 Census. The estimate for the number of people with FAE uses the rate of 9.1 per 1,000 for alcohol-related neurodevelopmental disorders.)

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<sup>1</sup> P. D. Sampson, A. Streissguth, F. Bookstein, R. Little, S. Clarren, P. Dehaene, J. Hanson and J. Graham Jr., "Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder," *Teratology*, Vo. 56, No. 5, November 1997.



Sources: Service Nova Scotia and Municipal Relations, *1999 Annual Report*; Newfoundland Statistics Agency, 2001; New Brunswick Vital Statistics; PEI Statistical Review, 2000

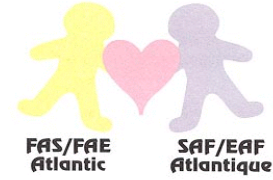
**Figure 2: Estimated Annual Number of FAS and FAE Births, Atlantic Provinces, 1999**

Figure 2 shows the estimated annual number of births where a child is born with FAS or FAE. (This estimate uses the number for births for each of the Atlantic provinces and applies the rate of 1 per 1,000 for FAS births, and 9.1 per 1,000 for FAE births, using the rate of alcohol-related neurodevelopmental disorders.)



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## FAS/FAE HIGH-RISK GROUPS



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It is estimated that 25% to 45% of women with chronic alcoholism will give birth to children with Fetal Alcohol Syndrome (FAS) if they drink heavily during pregnancy.<sup>1</sup>

Women with low levels of literacy, women of minority status, and women living in poverty are over-represented among mothers with children affected by FAS and Fetal Alcohol Effects (FAE).<sup>2</sup>

Studies of mothers of children diagnosed with FAS highlight some of the factors that may represent the root causes of the mothers' drinking: histories of severe unresolved abuse, mental health problems, living with partners who did not wish them to enter treatment, involvement in drinking sub-cultures, the fear of abandonment by family and friends if they stopped drinking, and alcohol-related organic brain dysfunction.<sup>3</sup>

Pregnancies that result in an alcohol-affected child may be unplanned or unwanted, and sometimes occur as a result of sexual assault.<sup>4</sup>

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<sup>1</sup> Anne Streissguth, "Fetal Alcohol Syndrome: A Guide for Families and Communities, 1997," quoted in *Fetal Alcohol Syndrome: A Hopeful Challenge for Children, Families and Communities*, Health Promotion and Programs Branch, Alberta/Northwest Territories Region, Health Canada, 1998.

<sup>2</sup> C. C. Ernst et. al., "Intervention with high-risk alcohol and drug abusing mothers: Three year findings from the Seattle model of paraprofessional advocacy, 1999," quoted in *Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of other Substance Use During Pregnancy*, Health Canada, Ottawa, 2000.

<sup>3</sup> S. K. Clarren, "The Development of FAS-Diagnostic and Prevention Network, A practical approach to FAS identification, treatment and primary prevention, 1999," quoted in *Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy*, Health Canada, Ottawa, 2000.

<sup>4</sup> J. L. Nanson, "Binge drinking during pregnancy: Who are the women at risk? 1997," quoted in *Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of other Substance Use During Pregnancy*, Health Canada, Ottawa, 2000.

Aboriginal people are over-represented among those with FAS. The Assembly of First Nations' submission to a Parliamentary Standing Committee in 1992 observed that "the level of FAS/FAE among First Nations' children represents a crisis situation."<sup>5</sup>

The drinking patterns during pregnancy of highly educated, high-income, married women place them at risk of having a child with FAS/FAE.<sup>6</sup>

For women who have already had one child with FAS, their risk of recurrence is very high, with an incidence estimate of 771 per 1,000.<sup>7</sup>

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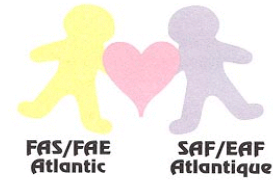
<sup>5</sup> The Assembly of First Nations, Presentation to the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women, 1992, quoted in Marilyn Van Bibber, *FAS Amongst Aboriginal Communities in Canada: A Review of the Existing Epidemiological Research and Current Preventative and Intervention Approaches*, For Seven Generations: An Information Legacy of the Royal Commission on Aboriginal Peoples (CD-ROM), Libraxus, 1997.

<sup>6</sup> Health Canada, *Canadian Perinatal Surveillance System – Alcohol and Pregnancy*, Health Canada, Ottawa, 1998.

<sup>7</sup> K. Huebert and C. Raftis, "Fetal Alcohol Syndrome and Other Alcohol-Related Birth Defects, 1996," quoted in *Fetal Alcohol Syndrome: A Hopeful Challenge for Children, Families and Communities*, Health Promotion and Programs Branch, Alberta/Northwest Territories Region, Health Canada, 1998.

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## ECONOMIC COST OF FAS/FAE



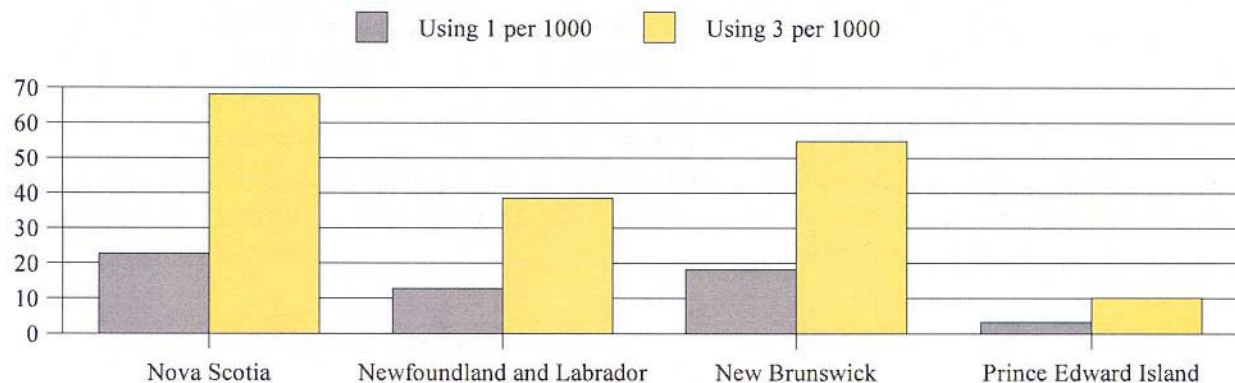
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Along with the medical and social costs of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), there is a tremendous economic cost associated with the resulting loss of human potential. Medical and therapeutic costs include the costs of interventions (special education, social workers), and the costs of care (home care, residential care, respite care). The economic costs of FAS/FAE include lost earnings, lost productivity, as well as the costs of the potential consequences of FAS, such as the costs of crime and incarceration.

One Canadian study has estimated the lifetime cost of FAS to be \$1.5 million per person.<sup>1</sup> This amount includes only direct medical, educational and social service costs; it does not include the cost of potential FAS consequences such as loss of productivity, crime and incarceration.

The estimated annual impact on each province is shown in Figure 1 (using an estimated life expectancy of 60 for individuals with FAS).

Each year in the four Atlantic provinces, the combined direct costs associated with FAS is almost \$57 million,<sup>2</sup> using the lowest estimate for the incidence of FAS (1 per 1,000).



Source: 2001 Census of Canada (population data)

**Figure 1: Estimated Annual Costs (millions of dollars), Atlantic Provinces, 2001**

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<sup>1</sup> Manitoba Child and Youth Secretariat, *Strategy Considerations for Developing Services for Children and Youth*, Manitoba Child and Youth Secretariat, 1997.

<sup>2</sup> This calculation assumes an average life span of 60 years for a person with FAS. Although no average life span was found in the literature on FAS, it was noted that FAS subjects in studies never exceeded 60 years of age, and that living with FAS makes a person more vulnerable to violence, suicide and early death.

These costs demonstrate the potential value of prevention and intervention activities. A prevention strategy that costs \$1.5 million and prevents one individual from being born with FAS can thus be seen as being cost-effective. An efficient prevention and intervention strategy could achieve huge long-term savings in medical, social service, policing and corrections expenditures by preventing many children from being born alcohol-affected.

Benefits can also be achieved with very little additional program expenditures. A correct diagnosis of FAS and an intervention plan that is appropriate can be very cost-effective. To use a school-based example, a child may be incorrectly diagnosed with Oppositional Defiant Disorder or Attention Deficit Hyperactive Disorder. If the child has FAS, a correct diagnosis can result in an intervention plan that is far more likely to succeed. The potential benefits of increasing the effectiveness of current interventions are very large, and depend on FAS education for those in the medical, justice, social services and education fields, who work with alcohol-affected people.

Properly designed and implemented FAS/FAE prevention and intervention services save money. Effective prevention activities reduce the number of people who need health and social services, and educational interventions. Prevention further reduces the costs of the consequences of FAS (such as crime). When FAS/FAE is diagnosed, interventions can be designed for an alcohol-affected person and thus make existing intervention services more effective.

Incarceration and other occurrences associated with the criminal justice system are known to be consequences of FAS/FAE. While we do not know what percentage of inmates have FAS/FAE, we do know that a very high percentage of FAS/FAE-affected people have been in trouble with the law or have been incarcerated. In an American study of 253 people with FAS or FAE, 60% had been in trouble with the law (which was defined as ever being charged, convicted, or in trouble with the authorities for any of a list of criminal behaviours), and 42% of adults had been incarcerated for a crime.<sup>3</sup> Given the costs of incarceration (estimated at between \$40,000 to \$100,000, depending on the type of institution, in 1998<sup>4</sup>), intervention strategies for people with FAS or FAE may be capable of reducing large expenditures in the justice system, and reducing the social and financial costs of crime.

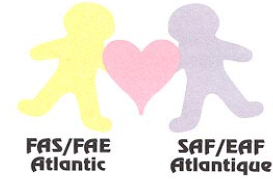
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<sup>3</sup> A. Streissguth, H. Barr, J. Kogan and F. Bookstein, "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), 1996," quoted in *Fetal Alcohol Syndrome: Implications for Correctional Services*, Correctional Services Canada, 1998.

<sup>4</sup> National Crime Prevention Centre, *Incarceration in Canada*, National Crime Prevention Centre, Ottawa, 1999.

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## FAS/FAE PREVENTION EFFORTS



**Primary prevention** actions prevent health problems before they occur. These include public awareness, alcohol-control measures, training of health professionals in the screening and diagnosis of alcohol abuse, life skills training and reproductive health training. The dangers of drinking during pregnancy is the major message in public awareness campaigns. This can be done with posters, warning labels, multi-media campaigns and outreach to inform about the risks of alcohol use while pregnant or able to conceive, and the benefits of protected sex. On a broader level, primary prevention includes population health approaches that address the socio-economic determinants of health, such as education, employment, income levels and social support.

It is recommended that when health promotion messages are developed, they be targeted to specific groups, that they avoid fear-arousing messages, and that they reflect the hierarchy of risk that exists.<sup>1</sup>

**Secondary prevention** actions identify and target those who are at risk. These include screening, early intervention programs, and services for women who may be at risk for having a child with Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE). Screening of pregnant women for their use of alcohol can take place in various settings, including justice, housing and health settings.<sup>2</sup> Early interventions include treatment for alcohol use, outreach to at-risk populations, and brief interventions with pregnant women to ensure they know the risks and the available options for treatment, support and health care.

**Tertiary prevention** includes actions that prevent the recurrence of FAS/FAE through treatment and attempts to lessen the cognitive, behavioural and social impacts of FAS/FAE. Activities include diagnosis and programs designed specifically for children with FAS/FAE and their caregivers, as well as treatment for women and their partners who already have one FAS/FAE child and plan to have more children.<sup>3</sup> Culturally appropriate and women-centred approaches, integration of services with a single point of access, intensive case management, and coordination of services that advocate for women can increase the effectiveness of tertiary

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<sup>1</sup> Health Canada, *Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy*, Health Canada, Ottawa, 2000.

<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

prevention activities. Punitive measures such as mandated treatment are not effective and deter women from seeking needed services.<sup>4</sup>

Dr. Ann Streissguth emphasizes the five Ps of prevention:<sup>5</sup>

1. public education
2. professional training
3. public policy
4. programs and services
5. parent and citizen activism.

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<sup>4</sup> Ibid.

<sup>5</sup> Ann Streissguth, "Fetal Alcohol Syndrome: A Guide for Families and Communities, 1997," quoted in *Fetal Alcohol Syndrome: A Hopeful Challenge for Children, Families and Communities*, Health Canada, Calgary, 1998.

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## RECOMMENDATIONS FOR ACTION



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Recommendations 1 to 4 are derived from the document, *Fetal Alcohol Syndrome: A Hopeful Challenge for Children, Families and Communities* (Health Promotion and Programs Branch, Alberta/Northwest Territories Region, Health Canada, 1998).

1. Work within a health promotion and prevention framework to address Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). This means addressing the broader social determinants as well as the systemic causes of alcoholism, poverty, violence, cultural breakdown, underemployment, lack of housing and lack of access to health care.
2. Facilitate early diagnosis of FAS/FAE.
3. Use existing capacity and relationships. Health Canada's Canada Prenatal Nutrition Program, Community Action Program for Children and Aboriginal Head Start are good programming sites for prevention and early intervention.
4. Encourage collaboration among governments (federal, provincial and territorial), with the private sector, and with non-governmental organizations.

Recommendations 5 to 7 resulted from Atlantic regional consultations, as reported in *Canada Prenatal Nutrition Program/Fetal Alcohol Syndrome and Effects Initiative, First Nations and Inuit Discussion and Feedback, Summary Report* (Childhood and Youth Division, Health Canada, 2000).

5. Implement provincial/regional coordination, to collaborate and address FAS/FAE issues using a teamwork approach.
6. Promote FAS/FAE education (including for health care professionals), as well as awareness raising among the general public.
7. Recognize cultural differences and incorporate traditional First Nations and Inuit values in the models used for FAS/FAE programs, alcohol treatment and other services.





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## FAS/FAE RESOURCES

Resources are listed under the following categories:

- General resources
- Resources for families and communities
- Educational resources (for teachers)
- On-line resources
- Videos
- Correctional services/justice system resources
- Costs of FAS/FAE
- First Nations and Inuit resources
- Prevention resources

### GENERAL RESOURCES

#### Organizations

Canadian Centre on Substance Abuse , 75 Albert Street, Suite 300, Ottawa ON K1P 5E7, tel.: (613) 235-4048 or (800) 559-4514, web site: [www.ccsa.ca](http://www.ccsa.ca)  
Clearinghouse for information.

Centre québécois de documentation en toxicomanie, 950 de Louvain Street East, Montreal QC H2M 2E8, tel: (514) 385-3490 ext. 1153, fax: (514) 385-5728, e-mail: [cqdt.cdc@ssss.gouv.qc.ca](mailto:cqdt.cdc@ssss.gouv.qc.ca), web site: <http://www.centredollardcormier.qc.ca/>

FAS/E Support Network of B.C., Suite 187, 151-10090 152nd Street, Surrey BC V3R 3X8, tel.: (604) 589-1854, e-mail: [fasnet@istar.ca](mailto:fasnet@istar.ca), web site: [www.fetalalcohol.com](http://www.fetalalcohol.com)

Motherisk Help Line, tel.: (877) 327-4636. The Motherisk Program at the Hospital for Sick Children in Toronto provides information, counselling and referral services to women throughout Canada.

Reproductive Health Section, Bureau of Reproductive and Child Health, Health Canada, HPB Building, Tunney's Pasture, Postal Locator 0701D, Ottawa ON K1A 0L2, tel.: (613) 941-2395, fax: (613) 941-9927, e-mail: [cpss@hc-sc.gc.ca](mailto:cpss@hc-sc.gc.ca), web site: [www.hc-sc.gc.ca/hpb/lcdc/brch/reprod.html](http://www.hc-sc.gc.ca/hpb/lcdc/brch/reprod.html)

For information on the Canadian Perinatal Surveillance System (CPSS), or to be added to the CPSS mailing list.

SAFERA, 845 Bord de l'eau Road, Saint-Henri QC G0R 3E0, tel.: (418) 882-2488, fax: (418) 882-2488, web site: [www.safera.qc.ca](http://www.safera.qc.ca)  
SAFERA is a francophone organization providing information, training and prevention activities related to FAS/FAE.

### **Published resources**

“Alcoolisme et grossesse : état des connaissances,” D. Kaminski, *Compétences médicales*, No.7, 1996, p.33.

*Best Practices. Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy* (2001), Canada's Drug Strategy Division, Health Canada, web site: [www.hc-sc.gc.ca/hppb/cds-sca/cds/pdf/BestpracticesEnglishclosed.pdf](http://www.hc-sc.gc.ca/hppb/cds-sca/cds/pdf/BestpracticesEnglishclosed.pdf)

*The Broken Cord* (1989), Michael Dorris, Harper Collins, New York.

*Dear World: We Have Fetal Alcohol Syndrome. Experiences of Young Adults* (1997), S. Berg et. al., FAS/E Support Network of B.C., Suite 187, 151-10090 152nd Street, Surrey BC V3R 3X8, tel.: (604) 589-1854, e-mail: [fasnet@istar.ca](mailto:fasnet@istar.ca), web site: [www.fetalalcohol.com](http://www.fetalalcohol.com)

*Directory of FAS/FAE Information and Support Services in Canada* (updated annually), Canadian Centre on Substance Abuse, 75 Albert Street, Suite 300, Ottawa ON K1P 5E7, tel: (613) 235-4048 or (800) 559-4514, web site: [www.ccsa.ca](http://www.ccsa.ca)

*Enhancing Fetal Alcohol Syndrome (FAS)-Related Interventions at the Prenatal and Early Childhood Stages in Canada* (2001), Canadian Centre on Substance Abuse, 75 Albert Street, Suite 300, Ottawa ON K1P 5E7, tel: (613) 235-4048 or (800) 559-4514, web site: [www.ccsa.ca](http://www.ccsa.ca).

*Fetal Alcohol Syndrome and Other Related Birth Defects*, 2nd Edition (1996), Kathy Huebert and Cindy Raftis. Distributed by Alberta Alcohol and Drug Abuse Commission, tel.: (800) 280-9616, web site: [www.aadac.com](http://www.aadac.com)

*Fetal Alcohol Syndrome. Diagnosis, Epidemiology, Prevention, and Treatment* (1996), edited by Kathleen Stratton, Cynthia Howe and Frederick Battaglia, Committee to Study Fetal Alcohol Syndrome, National Academy Press, 2101 Constitution Avenue NW, Lock Box 285, Washington, DC 20055, tel: (202) 334-3313.

*Fetal Alcohol Syndrome. A Guide for Families and Communities* (1997), Anne Streissguth, Paul H. Brookes Publishing Co., Maryland. Distributed by Copp Clark Professional, tel.: (800) 815-9417.

*Fetal Alcohol Syndrome: A Resource for Professionals* (2000), Saskatchewan Institute on Prevention of Handicaps, Saskatoon, tel.: (306) 655-2512, web site: [www.preventioninstitute.sk.ca](http://www.preventioninstitute.sk.ca)

*Guideline for the Diagnosis of Fetal Alcohol Syndrome, and Recommendations for the Prevention of FAS* (1999), Alberta Medical Association, Edmonton. Contact: The Alberta Clinical Practice Guidelines Program, 12230-106 Avenue NW, Edmonton AB T5N 3Z1, tel.: (780) 482-2626 or (800) 272-9680, web sites: [www.albertadoctors.org/resources/cpg/fas-diag-guideline.pdf](http://www.albertadoctors.org/resources/cpg/fas-diag-guideline.pdf)  
[www.albertadoctors.org/resources/cpg/fas-prevention-recommendations.pdf](http://www.albertadoctors.org/resources/cpg/fas-prevention-recommendations.pdf)

*A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects* (1995), Sandi Berg, Karen Kinsey, Jan Lutke and Donna Wheway. Distributed by FAS/E Support Network of B.C., Suite 187, 151-10090 152nd Street, Surrey BC V3R 8X8, tel.: (604) 589-1854, e-mail: [fasnet@istar.ca](mailto:fasnet@istar.ca), web site: [www.fetalalcohol.com](http://www.fetalalcohol.com)

*Situational Analysis. Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy* (2001), Canada's Drug Strategy Division, Health Canada.

*Substance Abuse and Pregnancy: Conceiving Women in the Policy-Making Process* (2000), Status of Women Canada, Ottawa, web site: <http://www.swc-cfc.gc.ca/publish/research/000828-0662286146-e.html>

*Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Final Report* (1996), A. Streissguth, H. Barr, J. Kogan and F. Bookstein. Distributed by the University of Washington School of Medicine, Fetal Alcohol and Drug Unit, 180 Nickerson Street, Suite 309, Seattle, Washington 98109, tel.: (206) 543-7155.

*What Doctors Need to Know About Fetal Alcohol Syndrome* (CD-ROM) (1998), A.E. Chudley and M.E. Moffatt, College of Physicians and Surgeons of Manitoba and the Manitoba Children and Youth Secretariat, Winnipeg.

## **RESOURCES FOR FAMILIES AND COMMUNITIES**

*Community Action Guide. Working together for the prevention of Fetal Alcohol Syndrome* (1998), Adult Addiction Services, British Columbia Ministry for Children and Families. To obtain a free copy send a self-addressed mailing label to Adult Addiction Services, British Columbia Ministry for Children and Families, P.O. Box 9717, Stn. Prov. Gov, Victoria BC V8W 9S1. Also available on the web site: [www.mcf.gov.bc.ca/child\\_protection/fas/fas\\_index.htm](http://www.mcf.gov.bc.ca/child_protection/fas/fas_index.htm)

*Empowering Our Communities on FAS/FAE: Training Manual* (1998), Mi'kmaq Native Friendship Centre. Contact: Della Maguire, Mi'kmaq First Nation Healing Society, tel.: (902) 420-1576.

*Fantastic Antone Grows Up! Adolescents and Adults with Fetal Alcohol Syndrome* (1999), J. Kleinfeld and S. Westcott (eds.), University of Alaska Press, Fairbanks.

*Fantastic Antone Succeeds! Experiences Educating Children with Fetal Alcohol Syndrome* (1993), J. Kleinfeld and S. Westcott (eds.), University of Alaska Press, Fairbanks.

*FAS/FAE: A Manual for Community Caring* (2000), FAS/E Support Network of B.C., Suite 187, 151-10090 152nd Street, Surrey BC V3R 3X8, tel.: (604) 589-1854, e-mail: [fasnet@istar.ca](mailto:fasnet@istar.ca), web site: [www.fetalalcohol.com](http://www.fetalalcohol.com)

*FAS/FAE and NAS (Neonatal Abstinence Syndrome) Prevention Projects Manuals* (1996 and 1993), Anne George. (Includes *FAS/FAE/NAS Community Prevention Guide*, *Guide for Parents, Teachers and Others Caring For Children with FAS/FAE/NAS* and *FAS/FAE/NAS Guide to Resources*.) Distributed by Vancouver YWCA, 535 Hornby Street, Vancouver BC V6C 2E8, tel.: (604) 895-5790.

*FAS Tool Kit*, Canadian Centre on Substance Abuse, 75 Albert Street, Suite 300, Ottawa ON K1P 5E7, tel.: (613) 235-4048 or (800) 559-4514, web site: <http://www.ccsa.ca/toolkit/Introduction.htm>

*Fetal Alcohol Syndrome-Effect: Developing a Community Response* (1999), Jeanette Turpin (ed.), Glen Schmidt, Fernwood Publishing. Distributed by Mosquito Books, 1600-15th Avenue, Prince George BC V2L 3X3, tel: (250) 563-6495. Focuses particular attention to the experience of remote and Northern communities.

*Fetal Alcohol Syndrome/Fetal Alcohol Effects, Training for Foster Parents* (2001), Federation of Foster Families of Nova Scotia, Box 2282, Halifax Central Post Office, Halifax NS B3J 3C8, tel.: (800) 565-1884 or (902) 424-3071.

*Fetal Alcohol Syndrome. A Guide for Families and Communities* (1997), Anne Streissguth, Paul H. Brookes Publishing Co., Maryland. Distributed by Copp Clark Professional, tel.: (800) 815-9417.

*It Takes a Community. A Resource Manual for Community Based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects* (1997), Aboriginal Nurses Association of Canada, 56 Sparks Street, Suite 502, Ottawa ON K1P 5A9, tel.: (613) 724-4677, fax: (613) 724-4718, e-mail: [info@anac.on.ca](mailto:info@anac.on.ca), web site: [www.anac.on.ca](http://www.anac.on.ca)



*A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects* (1995), Sandi Berg, Karen Kinsey, Jan Lutke and Donna Wheway. Distributed by FAS/E Support Network of B.C., Suite 187, 151-10090 152nd Street, Surrey BC V3R 8X8, tel.: (604) 589-1854, e-mail: [fasnet@istar.ca](mailto:fasnet@istar.ca), web site: [www.fetalalcohol.com](http://www.fetalalcohol.com)

*Parenting Children Affected by FAS: A Guide for Daily Living*, second edition, (1998), The Adoptive Council of Canada and the Society of Special Needs Adoptive Parents, Ottawa, web site: [www.mcf.gov.bc.ca/public\\_health/fas\\_guide1.pdf](http://www.mcf.gov.bc.ca/public_health/fas_guide1.pdf)

*Teaching Students with Fetal Alcohol Syndrome/Effects: A Resource Guide for Teachers* (1996), Julie Conry for the British Columbia Ministry of Education, Special Programs Branch. Distributed by Office Products Centre, B.C. Ministry of Education, 4248 Glanford Avenue, Victoria BC V8Z 4B8, fax: (250) 952-4442, web site: [www.bced.gov.bc.ca](http://www.bced.gov.bc.ca) (Also suitable for families.)

## **EDUCATIONAL RESOURCES**

*FAS/E and Education: The Art of Making a Difference* (1997), S. Berg et. al., FAS/E Support Network of B.C., Suite 187, 151-10090 152nd Street, Surrey BC V3R 8X8, tel.: (604) 589-1854, e-mail: [fasnet@istar.ca](mailto:fasnet@istar.ca), web site: [www.fetalalcohol.com](http://www.fetalalcohol.com)

*FAS/FAE and NAS (Neonatal Abstinence Syndrome) Prevention Projects Manuals* (1996 and 1993), Anne George. (Includes *FAS/FAE/NAS Community Prevention Guide*, *Guide for Parents, Teachers and Others Caring For Children with FAS/FAE/NAS* and *FAS/FAE/NAS Guide to Resources*.) Distributed by Vancouver YWCA, 535 Hornby Street, Vancouver BC V6C 2E8, tel.: (604) 895-5790.

*Fetal Alcohol Syndrome: Effective Teaching Strategies for FAS Children*, teachers guide and posters (2002), First Nations Education Council, tel.: (418) 842-7672, fax: (418) 842-9988, web site: [www.cepn-fnec.com](http://www.cepn-fnec.com)

*Teaching for the Prevention of FAS: A Resource Guide for Teachers of Health and Life Skills and Career and Life Management* (2001), Alberta Partnerships on FAS and the Learning and Teaching Resources Branch, Alberta Learning, 10<sup>th</sup> Floor, East Devonian Building, 11160 Jasper Avenue, Edmonton AB T5K 0L2, tel.: (780) 422-6326

*Teaching Students with Fetal Alcohol Syndrome/Effects: A Resource Guide for Teachers* (1996), Julie Conry for the British Columbia Ministry of Education, Special Programs Branch. Distributed by Office Products Centre, B.C. Ministry of Education, 4248 Glanford Avenue, Victoria BC V8Z 4B8, fax: (250) 952-4442, web site: [www.bced.gov.bc.ca/specialed/fas/](http://www.bced.gov.bc.ca/specialed/fas/) Includes an extensive list of recommended informational resources.

*Towards Inclusion: Tapping Hidden Strengths, Planning for Students Who Are Alcohol Affected* (2001), Manitoba Education, Training and Youth, web sites:

[www.edu.gov.mb.ca/ks4/specedu/fas/](http://www.edu.gov.mb.ca/ks4/specedu/fas/) or [www.mtbb.mb.ca/catalogue/en](http://www.mtbb.mb.ca/catalogue/en)

*What Early Childhood Educators and Caregivers Need to Know About FAS*, book and audio cassette (1996), Manitoba Education, Training and Youth. Contact: Manitoba Text Book Bureau, Box 910, Souris MB R0K 2C0, tel.: (204) 483-4040, web site: [www.mtbb.mb.ca](http://www.mtbb.mb.ca)

*What Teachers Need to Know About FAS*, Manitoba Education, Training and Youth. Contact: Manitoba Text Book Bureau, Box 910, Souris MB R0K 2C0, tel.: (204) 483-4040, web site: [www.mtbb.mb.ca](http://www.mtbb.mb.ca)

## ON-LINE RESOURCES

*Best Practices. Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy* (2001), Canada's Drug Strategy Division, Health Canada, web site: [www.hc-sc.gc.ca/hppb/cds-sca/cds/pdf/BestpracticesEnglishclosed.pdf](http://www.hc-sc.gc.ca/hppb/cds-sca/cds/pdf/BestpracticesEnglishclosed.pdf)

Canadian Women's Health Network, web site:

[www.cwhn.ca/network-reseau/network/network\\_vollno1/e-facts.html](http://www.cwhn.ca/network-reseau/network/network_vollno1/e-facts.html)

Centre for Addiction and Mental Health, University of Toronto, web site: [www.camh.net](http://www.camh.net)

*Community Action Guide. Working together for the prevention of Fetal Alcohol Syndrome* (1998), Adult Addiction Services, British Columbia Ministry for Children and Families, web site: [www.mcf.gov.bc.ca/child\\_protection/fas/index.html](http://www.mcf.gov.bc.ca/child_protection/fas/index.html)

*The Costs of Substance Abuse in Canada. A Cost Estimation Study: Highlights* (1996), Canadian Centre on Substance Abuse, web site: [www.ccsa.ca/docs/costhigh.htm](http://www.ccsa.ca/docs/costhigh.htm)

*Directory of FAS/FAE Information and Support Services in Canada* (updated annually), Canadian Centre on Substance Abuse, web site: [www.ccsa.ca/fasdir.htm](http://www.ccsa.ca/fasdir.htm)

FAS Alaska Fetal Alcohol Consultation and Training Services (FACTS), web site: <http://www.fasalaska.com>

FAS Bookshelf Inc., web site: [www.fasbookshelf.com](http://www.fasbookshelf.com) This is an Internet site to order resources such as books and videos on FAS and related topics.

FAS Community Resource Centre, web site: [www.come-over.to/FAS/](http://www.come-over.to/FAS/)

FAS/E Support Network of B.C., web site: [www.fetalalcohol.com](http://www.fetalalcohol.com)

*FAS Tool Kit*, Canadian Centre on Substance Abuse, web site:  
[www.ccsa.ca/toolkit/Introduction.htm](http://www.ccsa.ca/toolkit/Introduction.htm)

*Fetal Alcohol Syndrome: Implications for Correctional Service*, Correctional Services Canada, web site: [www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e.shtml](http://www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e.shtml)

Health Canada, Canadian Perinatal Surveillance System, web site:  
[www.hc-sc.gc.ca/hpb/lcdc/brch/reprod.html](http://www.hc-sc.gc.ca/hpb/lcdc/brch/reprod.html)

Health Canada FAS links, web site: [www.hc-sc.gc.ca/hppb/childhood-youth/cyfh/fas/links.html](http://www.hc-sc.gc.ca/hppb/childhood-youth/cyfh/fas/links.html)

Health Canada, Population and Public Health Branch, web site:  
<http://www.hc-sc.gc.ca/hppb/childhood-youth/cyfh/fas/>

*How much is too much when you're pregnant?* (fact sheet) Health Canada, web site:  
[www.hc-sc.gc.ca/english/magazine/2000\\_08/fas.htm](http://www.hc-sc.gc.ca/english/magazine/2000_08/fas.htm)

*Joint Statement: Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects*, Canadian Paediatric Society, web site: [www.cps.ca/english/statements/FN/cps96-01.htm](http://www.cps.ca/english/statements/FN/cps96-01.htm)

*Parenting Children Affected by FAS: A Guide for Daily Living*, second edition, (1998), Adoptive Council of Canada and the Society of Special Needs Adoptive Parents, web site:  
[www.mcf.gov.bc.ca/public\\_health/fas\\_guide1.pdf](http://www.mcf.gov.bc.ca/public_health/fas_guide1.pdf)

“A Report on the Health of British Columbians,” *Provincial Health Officer's Annual Report* (1997), web site: [www.hlth.gov.bc.ca/pho/ar/1997/report/index.html](http://www.hlth.gov.bc.ca/pho/ar/1997/report/index.html) Contains a special section on Fetal Alcohol Syndrome.

SAFERA, web site: [www.safera.qc.ca](http://www.safera.qc.ca)

Society of Special Needs Adoptive Parents (BC), web site: [www.snap.bc.ca](http://www.snap.bc.ca)

*Substance Abuse and Pregnancy: Conceiving Women in the Policy-Making Process* (2000), Status of Women Canada, web site:  
[www.swc-cfc.gc.ca/publish/research/000828-0662286146-e.html](http://www.swc-cfc.gc.ca/publish/research/000828-0662286146-e.html)

*Teaching Students with Fetal Alcohol Syndrome/Effects: A Resource Guide for Teachers* (1996), Julie Conry for the British Columbia Ministry of Education, Special Programs Branch, we site:  
[www.bced.gov.bc.ca/specialed/fas/](http://www.bced.gov.bc.ca/specialed/fas/)

*Towards Inclusion: Tapping Hidden Strengths, Planning for Students Who Are Alcohol Affected* (2001), Manitoba Education, Training and Youth, web sites:

[www.edu.gov.mb.ca/ks4/specedu/fas/](http://www.edu.gov.mb.ca/ks4/specedu/fas/) or [www.mtbb.mb.ca/catalogue/en](http://www.mtbb.mb.ca/catalogue/en)

*What is FAS/FAE?* (fact sheet) Health Canada, web site:

[www.hc-sc.gc.ca/hppb/childhood-youth/cyfh/fas/whatisfas.html](http://www.hc-sc.gc.ca/hppb/childhood-youth/cyfh/fas/whatisfas.html)

## VIDEOS

*Before I Was Born* (information package consisting of a poster, CD-ROM, video and video viewing guide) (2001), Pauktuutit Inuit Women's Association, 131 Bank Street, Ottawa ON K1P 5N7, tel.: (613) 238-3977, fax: (613) 238-1787, web site: [www.pauktuutit.on.ca](http://www.pauktuutit.on.ca)

*David with FAS: A Story of Fetal Alcohol Syndrome* (1996), Kanata Productions, National Film Board and Canadian Broadcasting Corporation, Ottawa. Available through the National Film Board, tel.: (800) 267-7710, web sites:

[www.nfb.ca](http://www.nfb.ca) or [cmm.onf.ca/E/titleinfo/index.epl?id=33183](http://cmm.onf.ca/E/titleinfo/index.epl?id=33183)

*Un drame évitable : les effets de l'alcool sur l'enfant à naître* (1992), Radio-Canada and Idiacom International for the series *Comment ça va?*. Available through Nuance-Bourdon Audiovisuel, 111 Broughton Road, Montreal QC H4X 1J9, tel.: (514) 486-9292.

*The Fabulous Quiz Show Video* (no date), Association for Community Living - Manitoba, 210-500 Portage Avenue, Winnipeg MB R3C 3X1, tel.: (204) 786-1607, fax: (204) 789-9850.

*Life Sentence (FAS and the Criminal Justice System)* (1997), CBC National Magazine, Toronto. Available through CBC Non-Broadcast Sales, Box 500, Station A, Toronto ON M5W 1E6, tel.: (800) 363-1281.

*One Drink Won't Hurt My Baby Will It?* (1996), Program Development Branch, Manitoba Education, Training and Youth, Winnipeg. Available through the Fetal Alcohol Syndrome Family Association, 210-500 Portage Avenue, Winnipeg MB R3C 3X1, tel.: (204) 786-1847.

*Precious Gift, A Fetal Alcohol Syndrome Prevention Video* (no date), Saskatchewan Institute on Prevention of Handicaps, 1319 Colony Street, Saskatoon SK S7N 2Z1, tel.: (306) 655-2512, web site: [www.preventioninstitute.sk.ca](http://www.preventioninstitute.sk.ca)

*Quelque chose à célébrer - Les jeunes mariés découvrent que l'alcool et la grossesse ne vont pas de pair* (1990), Health Programs Support Division, First Nations and Inuit Health Branch, Health Canada, 20th floor, Jeanne Mance Building, Postal Locator 1920A, Ottawa ON K1A 0L3, fax: (613) 954-8107.

*Vidéo sur le syndrome d'alcoolisme fœtal* (1995), Conseil en éducation des Premières Nations, tel.: (418) 842-7672, fax: (418) 842-9988.

## **CORRECTIONAL SERVICES/ JUSTICE SYSTEM RESOURCES**

*Fetal Alcohol Syndrome and the Justice System* (2001), Julieann Conry, (ed), Law Society of British Columbia and BC FAS Resource Society, Vancouver. Available from the Asante Centre, tel.: (604) 467-7101. e-mail: [info@asantecentre.org](mailto:info@asantecentre.org), web site: [www.asantecentre.org](http://www.asantecentre.org)

*Fetal Alcohol Syndrome: Implications for Correctional Service* (1998), Correctional Service of Canada, web site: [www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e.shtml](http://www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e.shtml)

## **COSTS OF FAS/FAE**

*The Costs of Substance Abuse in Canada. A Cost Estimation Study: Highlights* (1996), Single, Eric, Lynda Robson, Xiaodi Xie et. al., Canadian Centre on Substance Abuse, Ottawa, web site: [www.ccsa.ca/docs/costhigh.htm](http://www.ccsa.ca/docs/costhigh.htm)

*Strategy Considerations for Developing Services for Children and Youth* (1997), Manitoba Child and Youth Secretariat, Winnipeg.

## **FIRST NATIONS AND INUIT RESOURCES**

*Before I Was Born* (information package consisting of a poster, CD-ROM, video and video viewing guide) (2001), Pauktuutit Inuit Women's Association, 131 Bank Street, Ottawa ON K1P 5N7, tel.: (613) 238-3977, fax: (613) 238-1787, web site: [www.pauktuutit.on.ca](http://www.pauktuutit.on.ca)

*Empowering Our Communities on FAS/FAE: Training Manual* (1998), Mi'kmaq Native Friendship Centre. Contact Della Maguire, Mi'kmaq First Nation Healing Society, tel.: (902) 420-1576.

*FAS Amongst Aboriginal Communities in Canada: A Review of Existing Epidemiological Research and Current Preventative and Intervention Approaches* (1993), Marilyn Van Bibber, Royal Commission on Aboriginal Peoples Research Report.

*FAS Prevention Program* (resources for children and youth) (1999), Vancouver Friendship Centre, 1607 East Hasting Street, Vancouver BC V5L 1S7, tel.: (604) 251-4844

*It Takes a Community. A Resource Manual for Community Based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects* (1997), Aboriginal Nurses Association of Canada, 56 Sparks Street, Suite 502, Ottawa ON K1P 5A9, tel.: (613) 724-4677, fax: (613) 724-4718, e-mail: [info@anac.on.ca](mailto:info@anac.on.ca), web site: [www.anac.on.ca](http://www.anac.on.ca)

*Precious Gift, A Fetal Alcohol Syndrome Prevention Video* (no date), Saskatchewan Institute on Prevention of Handicaps, 1319 Colony Street, Saskatoon SK S7N 2Z1, tel.: (306) 655-2512, web site: [www.preventioninstitute.sk.ca](http://www.preventioninstitute.sk.ca)

*Training on FAS*, National Indian and Inuit Community Health Representatives Organization, P.O. Box 1019, Kahnawake QC J0L 1B0, tel.: (800) 632-0892 ext. 22, fax: (866) 281-2014, web site: [www.niichro.com](http://www.niichro.com)

## **PREVENTION RESOURCES**

*Enhancing Fetal Alcohol Syndrome (FAS) – Related Intervention at the Prenatal and Early Childhood Stages in Canada* (2001), Margaret Leslie and Gary Roberts, Canadian Centre on Substance Abuse, Ottawa ON, tel.: (613) 235-4048, web site: [www.ccsa.ca](http://www.ccsa.ca)

*The Fabulous Quiz Show Video* (no date), Association for Community Living - Manitoba, 210-500 Portage Avenue, Winnipeg MB R3C 3X1, tel.: (204) 786-1607, fax: (204) 789-9850.

*FAS Prevention Program* (resources for children and youth) (1999), Vancouver Aboriginal Friendship Centre, 1607 East Hasting Street, Vancouver BC V5L 1S7, tel.: (604) 251-4844.

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*Teaching for the Prevention of FAS: A Resource Guide for Teachers of Health and Life Skills and Career and Life Management* (2001), Alberta Partnerships on FAS and the Learning and Teaching Resources Branch, Alberta Learning, 10<sup>th</sup> Floor, East Devonian Building, 11160 Jasper Avenue, Edmonton AB T5K 0L2, tel.: (780) 422-6326.

*Your Child! Our Future! Fetal Alcohol Syndrome Prevention Kit*, Health Programs Support Division, First Nations and Inuit Health Branch, 20th Floor, Jeanne Mance Building, Postal Locator 1920A, Ottawa ON K1A 0L3, fax: (613) 954-8107, web site: [www.hc-sc.gc.ca/fnihb-dgspni/fnihb/chp/clearinghouse/index.htm](http://www.hc-sc.gc.ca/fnihb-dgspni/fnihb/chp/clearinghouse/index.htm)





# Order Form

Directory of FAS/FAE Information and Support Services in Canada

March 2003

To request a complimentary copy of the Directory, please fill in the form below and a copy will be sent to you by mail. You can access the Directory on the Internet at:

[www.ccsa.ca/fasis/fasall.htm](http://www.ccsa.ca/fasis/fasall.htm).

## Please send a copy of the Directory to:

Contact Name: \_\_\_\_\_

Organization: \_\_\_\_\_

Mailing Address:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Please add my name to the Canadian Centre on Substance Abuse mailing list to receive more information on FAS.

Mail or fax the completed form to:

FAS/FAE Information Service  
Canadian Centre on Substance Abuse (CCSA)  
75 Albert Street, Suite 300  
Ottawa, ON K1P 5E7

**Tel:** (613) 235-4048, ext. 223  
1-800-559-4514 (toll free)

**Fax:** (613) 235-8101

**E-Mail:** [fas@ccsa.ca](mailto:fas@ccsa.ca)



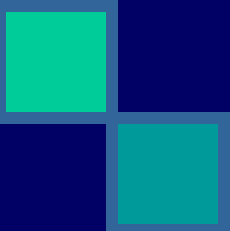

# FAS/FAE



Population and Public Health Branch  
First Nations and Inuit Health Branch  
Atlantic Region, Health Canada




# What is FAS?

- 
- Birth defects caused by prenatal alcohol exposure
  - Diagnosis requires a confirmed history of prenatal alcohol exposure
  - FAS exhibits three essential traits: growth retardation, central nervous system deficits and characteristic facial features
- 




# What is FAE?

- Fetal Alcohol Effects or partial Fetal Alcohol Syndrome (pFAS)
  - Presence of some, but not all, FAS symptoms
  - May be as severe as FAS
  - Diagnosis also requires confirmed history of prenatal alcohol exposure
- 




# Prenatal exposure to alcohol can cause:

- Intellectual deficits and learning disabilities
  - Multiple physical disabilities
  - Hyperactivity
  - Attention and/or memory deficits
  - Inability to manage anger
  - Difficulties with problem solving
  - Prenatal and postnatal growth deficiencies
- 

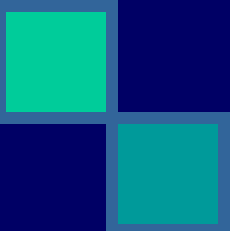



# Potential secondary conditions can include:

- Early school drop out
  - Alcohol and drug abuse
  - Problems securing and maintaining employment
  - Homelessness
  - Trouble with the law
  - Mental health problems
- 




# Life with FAS

- 
- FAS cannot be cured, but interventions can make life with FAS more successful
  - Protective factors known to help people with FAS, include early diagnosis, living in a stable and nurturing home, and not being a victim of violence
- 






# Incidence rates

- FAS: 1 to 3 per 1,000 live births
  - FAE: many times higher than FAS
  - 9.1 per 1,000 with alcohol-related neurodevelopmental disorder
- 




# High-risk groups

- Women with chronic alcoholism
  - Aboriginal people are over-represented
  - Risk of recurrence for those with one FAS child is very high (more than 70%)
- 

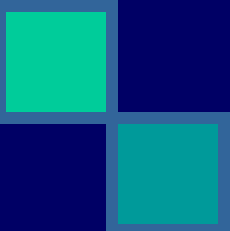



## High-risk groups (continued)

- US studies show FAS higher among women living in poverty, women with low literacy, women of minority status
  - Higher incidence of drinking while pregnant among high-income and highly educated women
- 

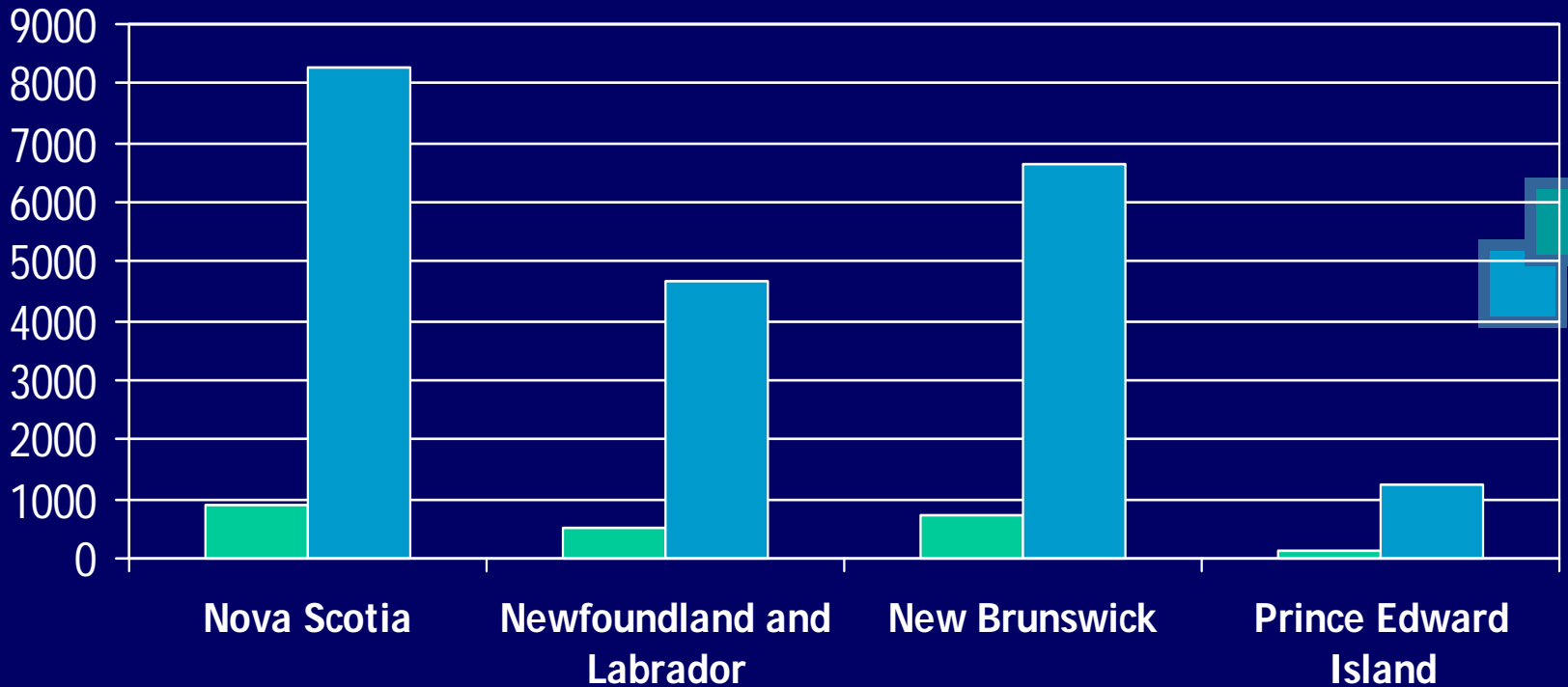


# Women at risk: Root causes

- 
- Histories of severe unresolved abuse
  - Mental health problems
  - Living with partners who do not wish them to enter treatment
  - Involvement in drinking sub-cultures
  - Fear of abandonment by family and friends if they stop drinking
  - Alcohol-related organic brain dysfunction
  - Pregnancies may be unplanned and unwanted
- 

# Number of people affected


FAS FAE



11




# New Brunswick

- Using 1 per 1,000, New Brunswick has more than 700 people with FAS
  - As many as 6,600 have FAE
  - 8 FAS births annually
- 

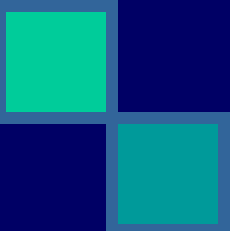



# Nova Scotia

- Using 1 per 1,000, Nova Scotia has more than 900 people with FAS
  - As many as 8,200 have FAE
  - 10 FAS births annually
- 




# Prince Edward Island

- 
- Using 1 per 1,000, Prince Edward Island has more than 130 people with FAS
  - As many as 1,200 have FAE
  - 1 FAS birth annually
- 



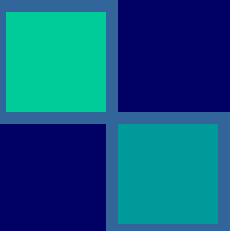



# Newfoundland and Labrador

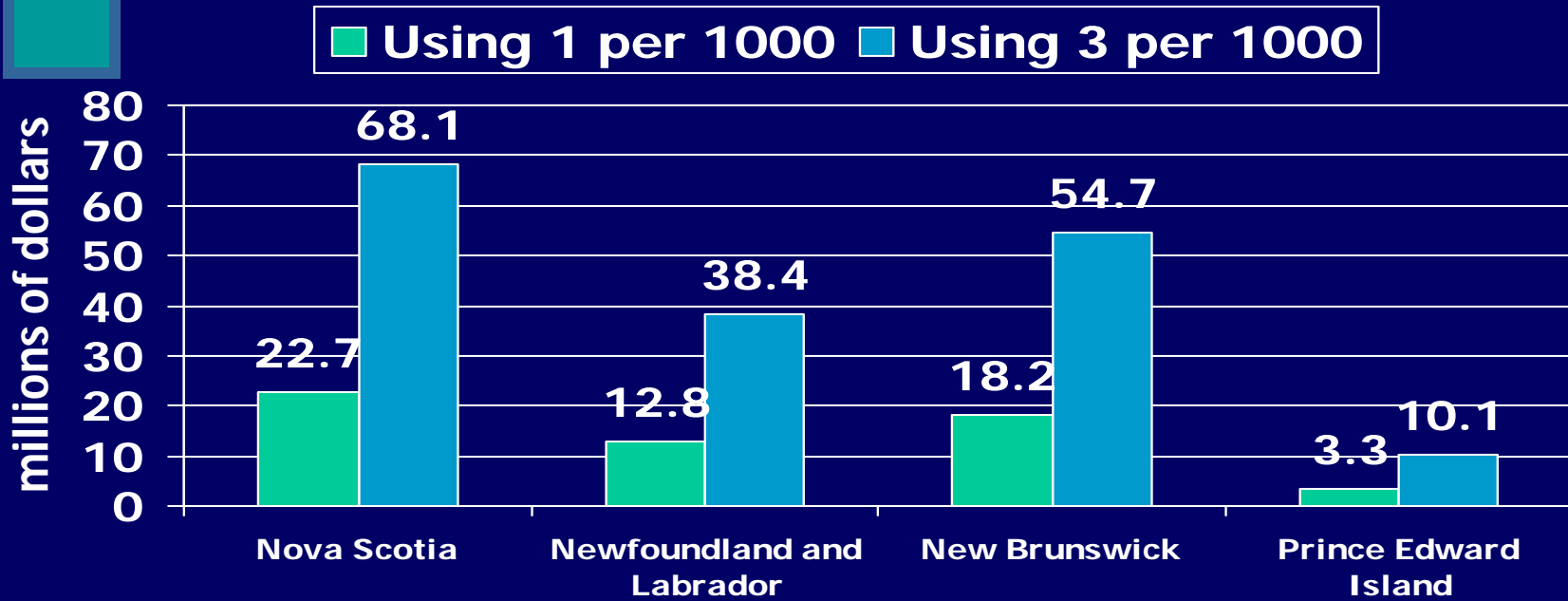
- Using 1 per 1,000, Newfoundland and Labrador has more than 500 people with FAS
  - As many as 4,600 have FAE
  - 4 FAS births annually
- 



# FAS costs in Atlantic Canada


- 
- Lifetime cost of \$1.5 million for direct costs, per occurrence
  - Annual costs of \$57 million (using lowest incidence rate, 1 per 1,000, and not including cost of FAE)
- 

# Annual FAS costs in Atlantic Canada






# Costs of FAS – potential savings from prevention

- A prevention strategy that costs \$1.5 million and prevents one child from being born with FAS could be considered cost-effective
- 




# Costs of FAS – potential savings from intervention

- Many children who have FAS/FAE are improperly diagnosed with ADHD and/or Oppositional Defiant Disorder
  - Proper diagnosis of FAS/FAE can lead to more effective interventions and can make interventions more successful without additional costs
- 

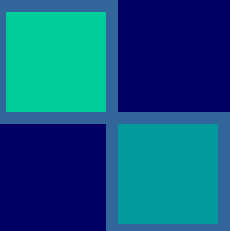



# Costs of FAS – potential consequences

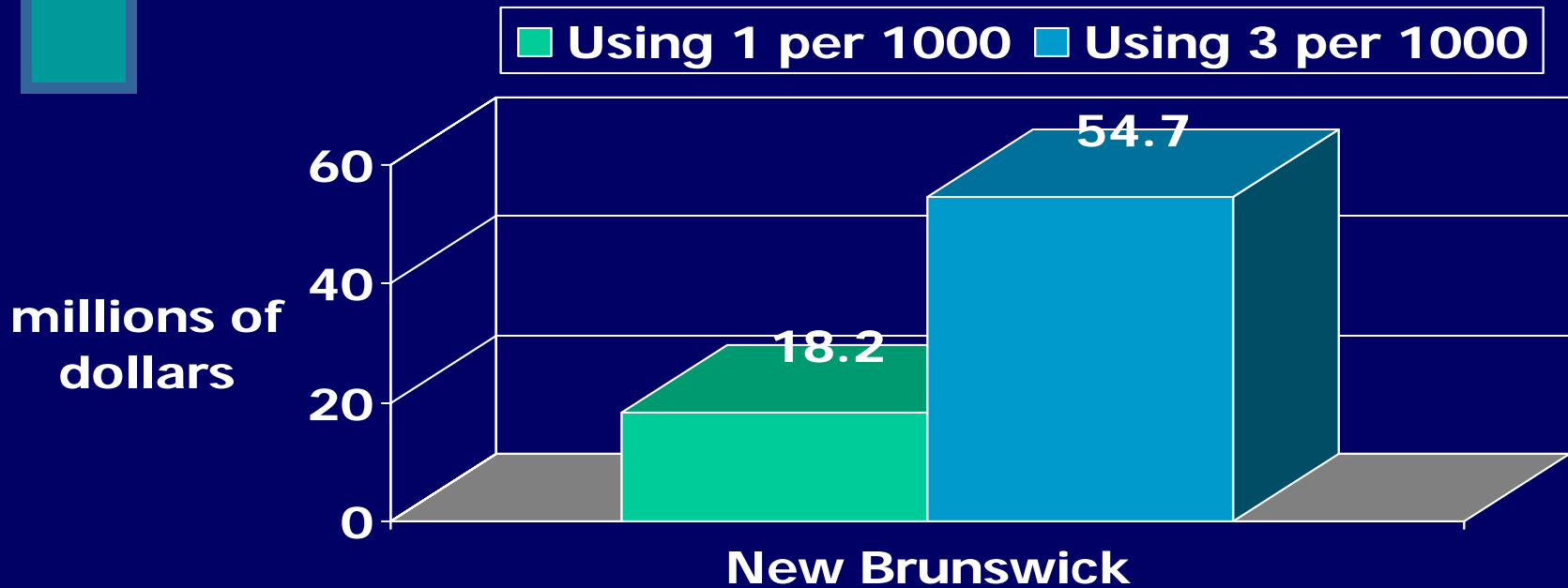
- US study showed 60% with FAS/FAE had been in trouble with the law and 42% of adults with FAS/FAE had been incarcerated
  - Costs of incarceration vary between \$40,000 and \$100,000 per person per year in Canada
  - Prevention and intervention can lower the number of alcohol-affected people who are incarcerated
- 



# FAS costs in New Brunswick

- 
- Lifetime cost of \$1.5 million for direct costs, per occurrence
  - Annual costs of \$18 million (using lowest incidence rate, 1 per 1,000, and not including cost of FAE)
- 

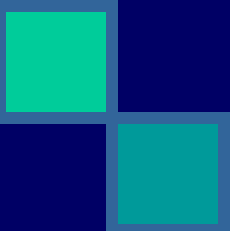

# Annual FAS costs in New Brunswick



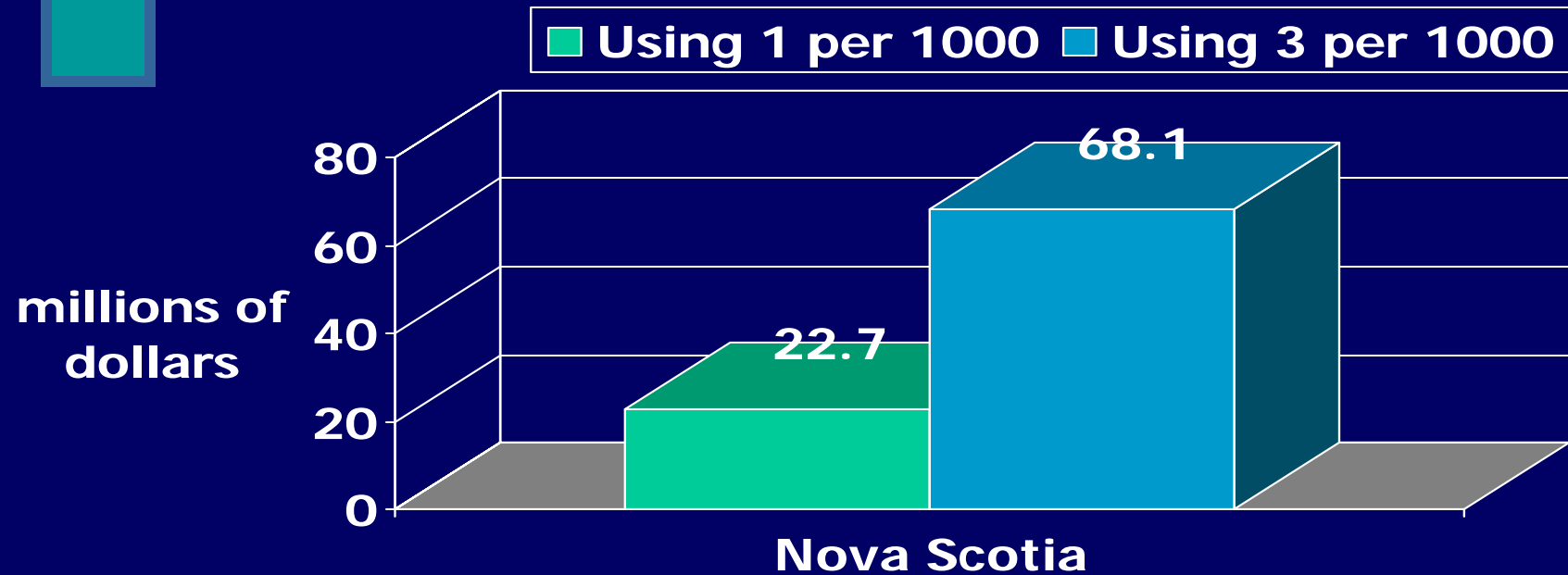




# FAS costs in Nova Scotia


- 
- Lifetime cost of \$1.5 million for direct costs, per occurrence
  - Annual costs of almost \$23 million (using lowest incidence rate, 1 per 1,000, and not including cost of FAE)
- 

# Annual FAS costs in Nova Scotia

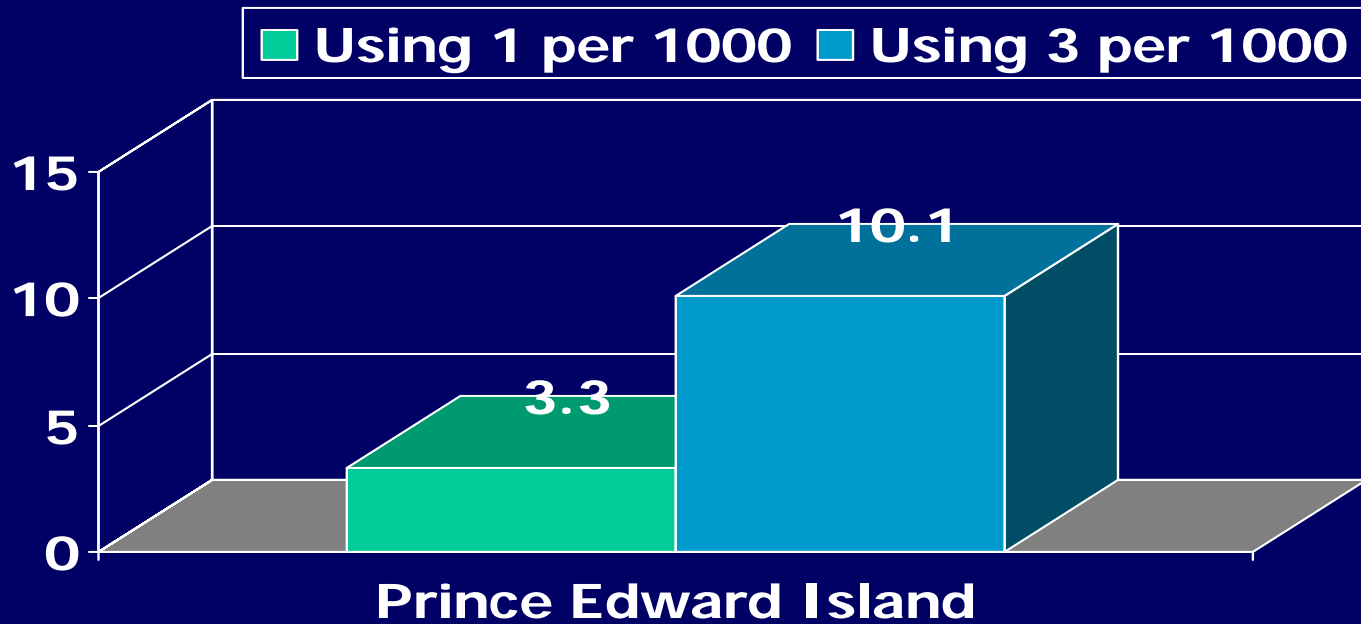




# FAS costs in Prince Edward Island


- Lifetime cost of \$1.5 million for direct costs, per occurrence
  - Annual costs of \$3 million (using lowest incidence rate, 1 per 1,000, and not including cost of FAE)
- 

# Annual FAS costs in Prince Edward Island

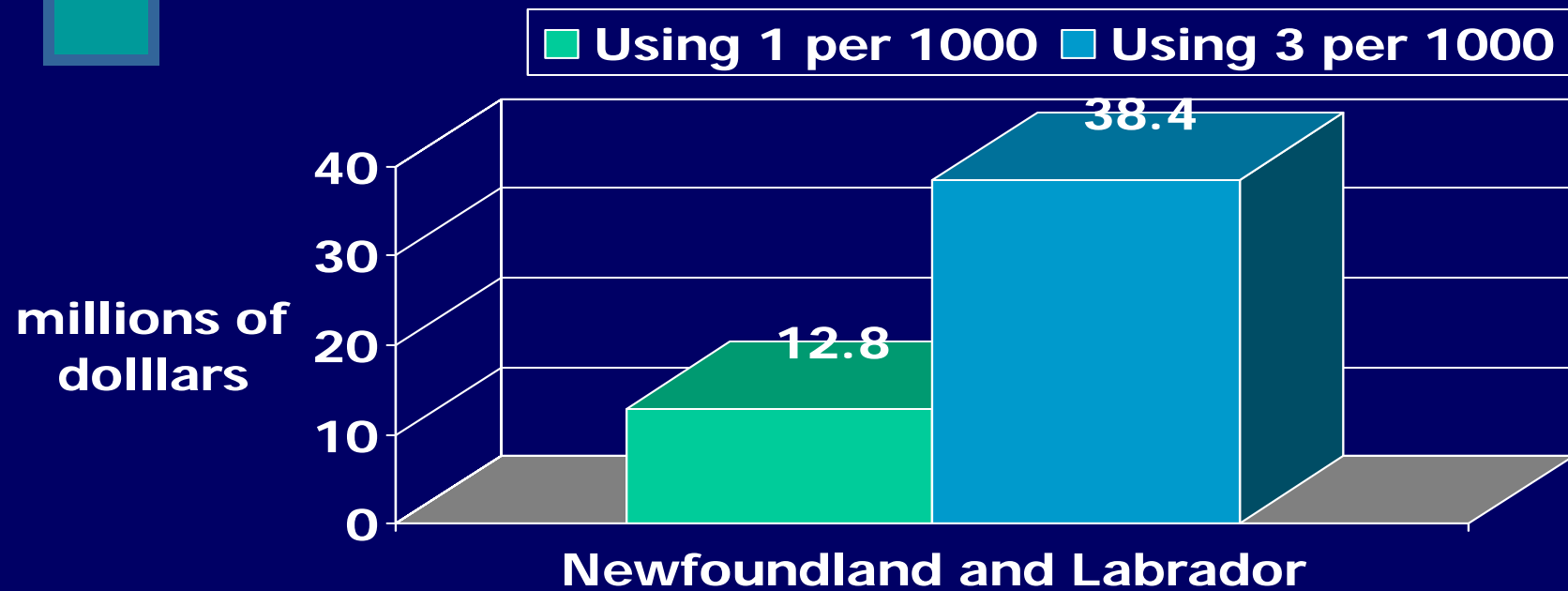




# FAS costs in Newfoundland and Labrador

- Lifetime cost of \$1.5 million for direct costs, per occurrence
  - Annual costs of almost \$13 million (using lowest incidence rate, 1 per 1,000, and not including cost of FAE)
- 

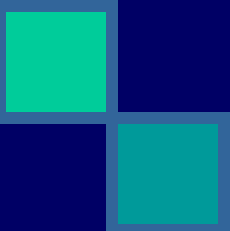

# Annual FAS costs in Newfoundland and Labrador



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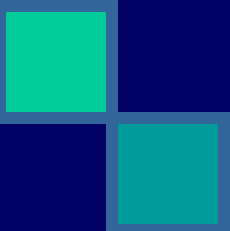



# FAS/FAE prevention

- 
- Primary – working with healthy populations
  - Secondary – working with at-risk groups
  - Tertiary – prevents recurrence and lessens effects
- 




# Primary prevention

- 
- Working with healthy populations
  - Awareness campaigns, training of health professionals, alcohol control measures, life skills training, health training
  - Population health approaches: addressing the broader impacts of social and economic inclusion, education, employment, income and social support
- 






# Primary prevention messages should:

- Be targeted to specific groups (not a single message for all groups)
  - Avoid fear-rousing messages
  - Reflect the hierarchy of risk that exists
- 




# Secondary prevention

- Working with groups who are at risk
  - Screening for alcohol use and abuse by pregnant women
  - Early interventions: treatment, outreach to at-risk populations, brief interventions with pregnant women to ensure they know the risks and the treatment options
- 



# Tertiary prevention


- Prevent recurrence and lessen effects
  - Working with FAS/FAE-affected people and their families
  - Proper diagnosis and treatment/interventions
  - Great potential to limit secondary disabilities
  - Working with women, and their partners, who have had a FAS/FAE-affected child
- 



# Effective tertiary prevention




Effective programs and services are:

- Integrated (single point of access)
  - Women-centred
  - Culturally appropriate
  - Coordinated, and advocate for women
  - Use intensive case management
- 




# Ineffective tertiary prevention

- Punitive measures such as mandated treatment are not effective and deter women from seeking needed services
- 

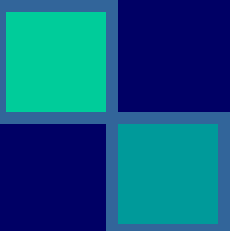



# Five Ps of prevention (Dr. Ann Streissguth)

1. Public education
  2. Professional training
  3. Public policy
  4. Programs and services
  5. Parent and citizen activism
- 

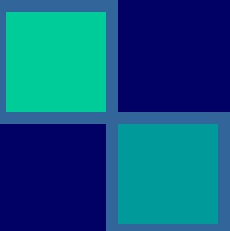



# Recommendations

- 
1. Address systemic causes of alcoholism.
  2. Facilitate early diagnosis of FAS/FAE.
  3. Use existing capacity and relationships for prevention work.
  4. Collaborate, coordinate and use a teamwork approach to move FAS/FAE work forward.
  5. Increase education and awareness.
  6. Recognize and incorporate cultural differences.
- 



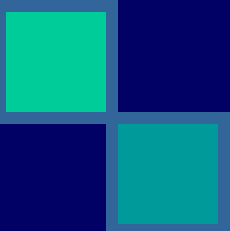

# Recommendation 1

- 
- Work within a health promotion and prevention framework to address FAS/FAE. This means addressing the broader social determinants, as well as the systemic causes of alcoholism, poverty, violence, cultural breakdown, underemployment, lack of housing and lack of access to health care.
- 






## Recommendations 2 & 3

- 
- Facilitate early diagnosis of FAS/FAE.
  - Use existing capacity and relationships. Canada Prenatal Nutrition Program (CPNP), Community Action Program for Children (CAPC) and Aboriginal Head Start (AHS) are good programming sites for prevention and early intervention.
- 



## Recommendation 4

- Collaboration among governments (federal, provincial and territorial), with the private sector, and with non-governmental organizations (NGOs).
  - Provincial/regional coordination, to collaborate and address FAS/FAE issues using a teamwork approach.
- 



## Recommendations 5 & 6

- FAS/FAE education (including for health care professionals), and awareness raising among the general public.
  - Recognize cultural differences and incorporate traditional First Nations and Inuit values in FAS/FAE programs, alcohol treatment and other services.
- 